

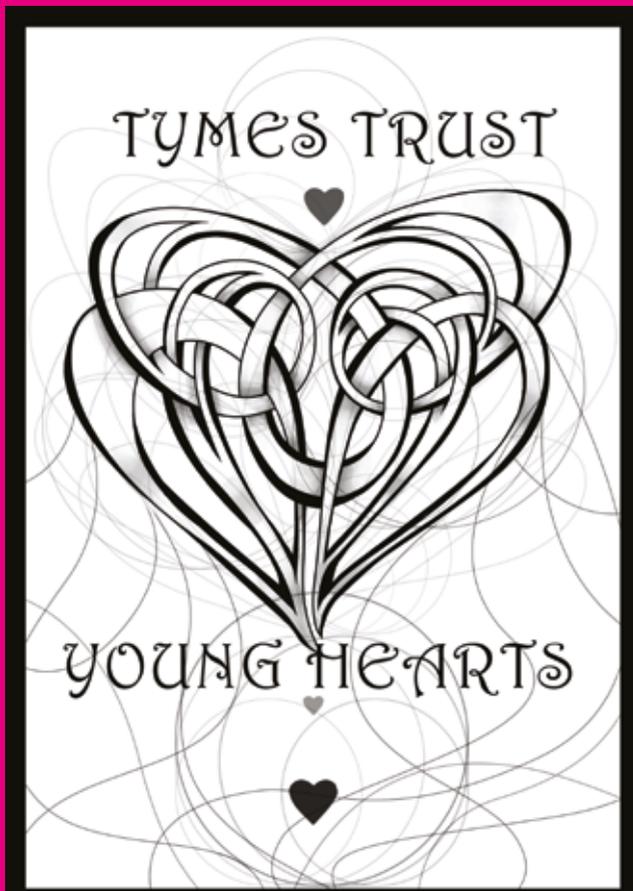


2016

# Tymes Tidings

Young Hearts Day on 29th November was spent packing your cards and gifts! This year Kathryn has designed you a bold black and white heart. Why not colour it?

Our year in pictures. See inside...



Young Hearts Design by Kathryn, Tymes Trust Young Officer



# Tymes Tidings



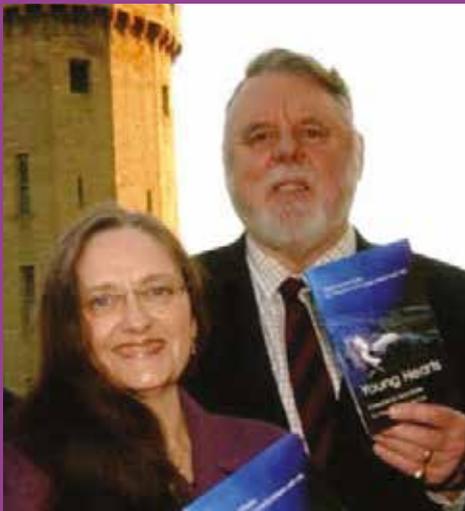
Tymes Trust's Young Hearts Day 29th November



Light a candle for the children with ME  
For the children need remembering you see  
It's a devastating illness  
So just take a moment's stillness  
To resolve we'll do our best to set them free.



Rhys Jones presents football coach Dan with a Young Hearts Award Certificate for Llanwern High School. "They have been so good to him" writes mum Dawn.



Terry Waite and Jane on the first Young Hearts Day at Warwick Castle on 29th November 2004.



Rhys' brother Carwyn dyes his hair to raise £137 for Tymes Trust!



**Lucy and Sophia coloured our Country Cottage.**



**Joanna calls hers "Jumping in Puddles"**



**Jorja painted our logo with her hands**



**Emma used gentle shades**



**Their Art Award Certificate**



**Mystery artist - who are you?**



Tymes Trust was part of the Supreme Court successful Appeal against the Scottish Government's law to make every child in Scotland have a state guardian (a Named Person) and to share their data with out permission. This "data" could just be hearsay. This historic win freed families from this oppressive law.



Tymes Trust's Scottish Officer Lesley Scott at a public meeting. She has given numerous press interviews and addressed Roadshows all over Scotland.



Sadia's mum Azima is taking her own legal action against a school. The Leader of the Opposition made a home visit.



# Tymes Tidings

At the House of Lords



Fabian McDonald at the House of Lords with host Lord Clement-Jones.



In June we held our Awards Ceremony at the House of Lords with Nisai Learning.



Tymes Trust Young Officer  
Daniel Scaddan



US journalist David Tuller receives the Tymes Trust Award for Scientific Journalism for his expose of the PACE trial.





# Summer



**The T Rex In The Room  
and  
Paediatric ME, CFS, SEID For  
Families And GPs**



*Our 2016 leaflet and Jane Colby's speech given at the House of Lords to introduce it. Are there risks with graded exercise therapy? NICE Guidance and education.*

**Printed copies free for a limited period.**



**Essex coast in Summer**

At the House of Lords we launched our new GP Leaflet about why ME is different from other fatiguing illnesses and why exercise makes people worse. Medical references. Find it at [www.tymestrust.org](http://www.tymestrust.org) with Jane's speech introducing it.



**Chair Keith Harley makes time to relax for once**



**Our House of Lord teddy**



**Champion golfer Padraig Harrington wins again in Portugal! See his lovely message to us at [www.tymestrust.org](http://www.tymestrust.org)**



**Jane can't stand the light!**





We are concerned about the belief in Graded Exercise Therapy and Cognitive Behaviour Therapy for ME. When it doesn't work, families are being reported to social services, yet NICE recommends them. We are working with the Countess of Mar to change that. In our Twitter poll asking whether MAGENTA (a 'PACE trial for kids') should be suspended until the PACE data was independently analysed, 100% of voters agreed. Now FITNET, a new trial of CBT in children (leading to GET) has been widely publicised.

Our Executive Director Jane Colby was interviewed by the Today Programme and Victoria Derbyshire Show. She explained the problems with FITNET.

We also do not support MEGA, the new study involving the same researchers. Our MEGA statement is at [www.facebook.com/tymestrust](http://www.facebook.com/tymestrust) including Jane's media interviews. It links to our FOI expose of the research Collaborative, which can also be found in the Reports section of our publications at [www.tymestrust.org](http://www.tymestrust.org).

## We note

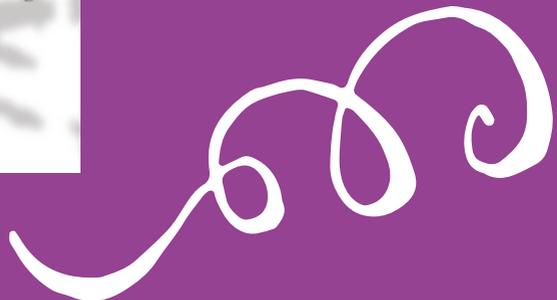
In the run-up to the full formation and launch of the Collaborative, a meeting was recorded by the Science Media Centre (SMC)'s outgoing head of Mental Health (details below). In attendance were key persons now involved with the Collaborative. Under their heading 'Harassment' (of researchers) they list:

- Freedom of Information Requests
- Complaints to the GMC and various institutions
- Parliamentary Questions

**The Young ME Sufferers Trust**  
**Shining A Light On The CMRC Setup**  
(Minutes And Emails Obtained Under FOI)  
*A Report from Tymes Trust - the inside story of the UK CFS/ME Research Collaborative*



Our Report is based, not on speculation or conjecture, but on direct evidence from emails exchanged by the participants. We think this is key reading for the ME community. We are publishing the text here in case you have not seen it yet.





# I think the belief in 'treatment' is currently the single biggest problem

Dr Nigel Speight's opinion



Tymes Trust retweeted



**Tina Rodwell** @TinaRodwell1

4d

Tymes Trust help to support mothers and children solid advice and a comforting word when the rest of the world is mad!

**CFS is not M.E.** @MEisNotFatigue  
@notafreebird @tymestrust  
the Chief Exec. of a major Children's #ME charity says "CFS" is a nonsense. Let's ALL support her for saying it.



Katie and her dad made terrific posters for the international Millions Missing event.

We love getting your cards and messages. See our daily tweets on Twitter @tymestrust and @JaneCColby We have a great group of followers who enjoy the mutual support and friendship. No need to tweet – you can just follow along. Our news is also posted at [www.facebook.com/tymestrust](http://www.facebook.com/tymestrust) (no need to join Facebook as it's a public page).





## It's Christmas!



One of Seb's cousins at Halloween. He dyed himself purple and was the special guest at the Tea Rooms overlooking the river



The Tymes Trust Christmas Tree

where to email it. Let us know when it's ready (email me on the Contact Us form at [www.tymestrust.org](http://www.tymestrust.org)) and I'll send prizes for every picture I get, till I run out!



Mr Harley's Christmas Gifts

This year I have been given some Absolutely Unique presents to send you. These KnitWits were hand knitted especially for Tymes Trust by Trustee Margaret Ross, from safe craft materials. If you would like one, let me know on an email or write me a nice letter or card. If I run out I'll find you another cuddly toy instead. Try not to wear yourself out at Christmas! I always say that, don't I?



Seb has found his cosy Christmas Stocking again and hopes Santa will agree...



Seb says: I was going to keep my bucket for Summertime – but I've used it for most of the year to sit in and think. I am a Great Thinker. What about you? Can you draw me a picture of your favourite cuddly toy? Post it to Seb at the address below or you can take a photo – we'll tell you

